



University of Salford
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Centre for Nursing &
Midwifery Research

Evaluation of Salford Carers' Development Service (SCDS)

FINAL REPORT

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June 2011

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Social Care**

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PART 1

Introduction

“A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.”

(Department of Health 2008)

Between July 2007 and July 2009, a Carers' Support Service operated within one area of Salford City (Charlestown and Lower Kersal). This original service was the pre-cursor to a different service known as the Salford Carers' Development Service (SCDS). The SCDS was set up to meet carers' support needs in other areas of the City from August 2009 using the learning from this original service. The SCDS comprised staff who had provided the Charlestown and Lower Kersal service and its senior management remained the same. The plan for the SCDS was that it would focus on three other areas of the City consecutively, with each one receiving dedicated SCDS input for a year-long period. In spring 2010, the SCDS manager (Chief Executive of Unlimited Potential – a social enterprise in the form of a community benefit society) negotiated an evaluation study to be undertaken by researchers from the University of Salford's School of Nursing and Midwifery. Groundwork for the evaluation took place over the summer of 2010, with data collection commencing in October 2010 and completing in February 2011. This report shares the findings from this project which is an example of public engagement activity.

PART 2

Background

The Service

When the Salford Carers' Development Service (SCDS) was set up, it built on a previous service (Carers' Support Service) to support carers in the Charlestown and Lower Kersal area of the City of Salford that had been commissioned from July 2007 to July 2009. Since the original funding for this service in that area ceased, a Carers' Drop-in group has continued to meet and was helped to develop its own constitution so that it could continue to run as a carer-led group.

From 1st August 2009 to 31st March 2011, the Community, Health and Social Care directorate at Salford City Council, commissioned a new service to deliver carers' support in areas prioritised in the current Salford Carers' Strategy. The SCDS was set up to tailor the effective carer support mechanisms employed in the Charlestown and Lower Kersal area and apply these to meet the local needs of carers in the priority areas of Claremont and Weaste, Little Hulton and Walkden, and Irlam and Cadishead. Each area was to be focused on by the SCDS for a year and whilst funding was made available for the first two years, funding for the third area (Year 3) was not and it was intended that this would be sought at a later date. This further funding has now been secured. A key aspect of the evolved SCDS service was that it was to develop a local response to the top priority of carers in each area that would be sustainable beyond the 12 months that the SCDS focused there. In this way the SCDS was very much community-based rather than client-based or case-based.

The SCDS centres around the activities of a SCDS Worker who had previously undertaken the role of the Carers' Support Service Worker. The SCDS Worker's 'outreach' way of working involves getting to know statutory and voluntary agencies in an area, building a rapport with local people, perhaps through some kind of community event and reaching out to carers within neighbourhoods. Carers would then have their needs identified and a response would be tailored by the SCDS Worker to meet those needs. The intention is for much of the role to be about

signposting carers to other available sources of support and so the SCDS Worker seeks to quickly identify who the key local agencies are such as Integrated Care Teams, GPs, social workers and so on. A database of carers is maintained by the SCDS Worker and these are identified largely through her substantive outreach role, whereby she visits community forums (cafes, GP surgeries, shops, community centres etc) and strikes up a conversation with people. Word of mouth is the other main means of the SCDS Worker identifying carers who may need support and for carers to become aware of the SCDS. Leaflets are also distributed widely and other promotional materials have been made such as DVDs.

At the time of this evaluation project, the SCDS had recently moved on from the initial focus area (Claremont and Weaste) where carers had independently come up with the idea of a Carers' Drop-in group, similar to that previously developed in Charlestown and Lower Kersal. This had been set up with help from the SCDS Worker and had undergone a period of becoming a truly carer-led group with an appointed committee and an action plan to seek its own funding from the Lottery fund (secured at the time of publishing this report). There was no expectation that the second area of Little Hulton and Walkden would also seek to have a similar Carers' Drop-in group and an event had been undertaken in late 2010 to meet with carers from that area to invite their views as to what their needs were so that the SCDS could respond to these. The only restriction on the kind of carers that the SCDS Worker may identify and support is that they must be aged 16 years and over. There are arrangements in place for her to be able to refer on widely to agencies including statutory ones in a relatively informal way, thereby arranging social worker visits or various kinds of assessments for carers with relative ease.

Literature Overview

The terms 'service users' and 'carers' are often used in unison, but carers often have different perspectives and needs from people they may have a role in caring for. The term 'carer' has been variably defined. The Department of Health (DH) in 2008 described a carer as someone who *"...spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems."*

A carer may be a family member, including a child or young person, who lives with the person they care for, or family, friends or neighbours who live elsewhere. In 2001, the Census of Population revealed that in the UK about 6 million people were providing unpaid care of this type. Carers can be of any age. In the North West in 2001 there were 31,029 carers aged 5-19 years. Of these, 2,586 provided 50 or more hours of care per week; 14,542 were under 16 years old; and 810 were themselves in poor health. The situation for older carers in the North West is similarly eye-opening with 22,572 carers aged 65 years or over and 4,449 aged over 85 years old (among them 2,295 providing 50+ hours of care weekly) (DH 2010).

The onset of a caring role can be gradual or sudden such as following an accident or acute illness (DH 1999) and carers may have little or no time to acclimatize to the new role and the demands it places upon them. These impacts may be at a physical, emotional and relational level, as well as broader effects on finances and engagement in paid employment (Edwards *et al* 2008).

The onus has been on health and local authorities and other local and regional agencies across the public, private and voluntary sectors to identify, facilitate and/or deliver ways to better meet the needs of carers. To frame action, the Government has produced two National Carers' Strategies in recent years.

The *National Carers' Strategy* (DH 1999) originally highlighted three key areas for action:

1. Information for carers, so that they become real partners in the provision of the care to the person they are looking after, with the means to provide that care as well as they all wish to, and with wider and better sources of information about the help and services which are available to them.
2. Support for carers, from the communities in which they live, in the planning and provision of the services that they and the person they are caring for use, and in the development of policies in the workplace which will help them to combine employment with caring.

3. Care for carers, so that they can make real choices about the way they run their lives, so that they can maintain their health, exercise independence, and so that their role can be recognised by policymakers and the statutory services.

Following on from this the Government White Paper, *Our health, our care, our say* (2006) announced a New Deal for Carers which included a range of new measures to support carers, including:

- The establishment of a national helpline for carers
- Specific funding for the creation of an expert carers' programme
- Specific funding for short-term home-based respite care for carers in crisis or emergency situations

The more recent *National Carers' Strategy* (DH 2008) commendably advances earlier ambitions to improve the situation for carers by earmarking £255 million for initiatives including planned short breaks for carers, support for carers to enter or re-enter the job market; and improved support for young carers. Other commitments in the strategy include: pilots to explore annual health checks for carers, the ways in which the NHS can better support carers and ways to provide more innovative breaks for carers; training for GPs; a more integrated and personalised support service for carers; accessible information and targeted training for key professionals.

The *Carers in the Region* profile fact sheet for the North West (DH 2010) sets out useful information for agencies such as local authorities so that they are made better aware of carers' needs and the existing support and provision available to assist them in the region. This document highlights a range of local responses aimed at improved support for carers including Carers' Strategy Steering Groups, Carers' Forums and local initiatives aimed at reaching less visible carers such as young carers and those with ethnic minority backgrounds. A particular difficulty with such local initiatives has been to sustain them especially when such approaches have often been in receipt of temporary, short-term funding. Where initiatives have existed, evaluation has generally been absent or minimal with some exceptions (Williamson *et al* 2009). Increasingly, carers are being encouraged to be partners in

decision making for health care planning and delivery (Walker and Dewar 2001) and associated service development. Going beyond involvement in decision making, the last decade has seen a proliferation of community led and community embedded ventures aimed at supporting carers. One such initiative is the Salford Carers' Development Service reported upon here.

There is an obvious immediate economic benefit of informal unfunded care being provided by relatives or friends of people being cared for. Without informal caring there may result a greater demand on statutory services including the need for hospitalization or preventable temporary or permanent moves into nursing and residential care settings (DH 1999). However this needs to be balanced against the negative impacts of caring on the carer that are well documented in terms of increased stress (Carers UK 2004), poor health (Carers Scotland 2011) and loss of productivity such as paid employment. For example young carers aged 16-19 who provide 20 or more hours of care per week may be less able to gain formal qualifications needed to progress in the job market (DH 2010). For younger carers, school work may commonly suffer due to poor attendance (Mahon and Higgins 1995).

These facts and figures have clear implications for the ability of carers to have a life of their own beyond their caring role should they wish to do so. Carers trying to hold down paid employment may be particularly challenged by the amount of care they undertake or the time of day or night that the care takes place. Whilst caring can be for people who do not have a health need e.g. routine child care, those who are cared for often have health conditions requiring attention which may or may not be classed as disabling. Older people with multiple health issues may present particular challenges for their carer but others also have what may be complex needs e.g. people of any age with mental illness. The complexity of caring for people should not be underestimated nor should the individual nature of each caring relationship go unrecognised. Similarly, whilst the caring role may be taxing it is not uncommonly perceived as a welcome duty giving much satisfaction (Ribiero and Constanca 2008).

PART 3

Evaluation Design

Evaluation aim

The aim of the evaluation project was to identify the value that carers who had used the Salford Carers' Development Service (SCDS) placed upon it.

Our objective within that was to 'give voice' to a broad cross section of carers who had used the SCDS to best illuminate its function and perceived impact.

People's involvement

Members of two local Carers' Drop-in groups met with the evaluation team three times to inform the evaluation project. The first occasion was to introduce the evaluation team and the project and to ask for their support in taking the project forward. The second meeting was to discuss the evaluation design and agree the evaluation interview questions in detail. This way we could be sure we were going to ask the questions of concern to carers and not just those of the evaluators and project commissioners. Lastly, carers read and commented on a draft report of findings prior to them being finalised, as a means of checking that they accurately reflected their views. Carers were asked if the findings resonated with them and whether they perceived any gaps, contradictions or surprises which we could then check against what people told us in the interviews. The carers we spoke to were very supportive of our work with them and helped to improve its design.

We also met with the SCDS commissioner and manager, and the SCDS Worker to gain and incorporate their views on the project design and questions to be asked, which we acted upon.

Sampling

It was agreed to gain the views of approximately 10 carers. These would include carers who had used the SCDS through its outreach remit, as well as carers who had gone on to be members of a Carers' Drop-in group set up by the SCDS. We were also asked to

speak with carers who were newly introduced to the SCDS shortly after the SCDS Worker had refocused her input in a new area of Salford (Little Hulton and Walkden), to gain their aspirations for the Service.

It was also considered helpful to speak to a small number of carers from the Charlestown and Lower Kersal Carers' Drop-in group (developed under the auspices of the former Carers' Support Service) to gain a historical insight into the development of the SCDS.

We wanted to gain a wide range of views and so sought a 'maximum diversity' sample of participants. We in fact spoke to 12 carers as 2 participants were interviewed with their partners present, and these couples viewed themselves as carers of each other. Therefore 12 voices were gained in total. These are presented as 10 case studies made up of ten individuals and two pairs.

Interview guide

An interview guide was developed with 13 questions in it. A few of the carers who advised on the design of the evaluation and the questions to be asked, then went on to be participants and were interviewed. Interview questions were developed from discussions with the SCDS commissioner, SCDS manager, SCDS Worker and the original SCDS Service Plan/Contract.

Data collection

The SCDS Worker identified potential participants to us and from these we selected a wide ranging sample to reflect the varying characteristics of carers in terms of age, gender, time as a carer, caring situation, whether a Carers' Drop-in group member or not, whether they had been identified to the SCDS Worker through her outreach role or not, and people new to the SCDS because it had only just moved to their area (to gain their aspirations for its development there).

The SCDS Worker gained potential participant's permission to have their contact details passed on to the evaluation team who made contact and set up an interview appointment. Interviews were undertaken in carer's own homes or a community venue of their choice. Information sheets were talked through to clarify the

purpose of the interviews and written consent was gained for the formal interviews. With permission, most interviews were digitally recorded. For three informal interviews at a community event, hand written notes and a verbal consent only, were taken.

The questions were well understood by participants and none had to be altered. Interviews lasted between 10 minutes and 1 hour and 15 minutes but on average lasted about 40 minutes.

Ethical considerations

As a service evaluation (not a research study) there was no requirement for research ethics approval. However, the evaluation was undertaken to the same ethical standards as would be the case in research. For example all participants were made aware that their stories may make them identifiable by people in their local communities. All were happy to continue although real names are not disclosed in this report.

PART 4

Findings

Case studies: carer's voices

Participant's real names have not been used.

Case study 1 – Jim & Joyce's story
Case study 2 – Peter's story
Case study 3 – Barbara's story
Case study 4 – Sandra's story
Case study 5 – Neil's story
Case study 6 – Jamie's story
Case study 7 – Carol's story
Case study 8 – Andy's story
Case study 9 – Lee & Katie's story
Case study 10 – Pauline's story

Case study 1 – Jim & Joyce's story

Jim and Joyce are a couple who care for each other as they both have a range of chronic health conditions. They came across the former Carers' Support Service in the Charlestown and Lower Kersal area approximately four and a half years ago. At that time, Joyce had been caring for a friend for a considerable number of years who suffered from depression. The friend passed on a message from the Carers' Support Service Worker (who later went on to become the Salford Carers Development Service Worker [SCDS] in subsequent areas) to encourage Jim and Joyce to help do something for carers in their area. They talked with the Carers' Support Service Worker and formed a small committee to help develop a group which the Carers' Support Service Worker had initiated. They later took on roles within this group as Treasurer and 'Meeter and Greeter'.

For this couple much of their involvement with the Carers' Support Service was in relation to attending and contributing to the running of this group and over a long period of time. It developed into a very active group with large numbers of carers regularly attending the two hour meetings held on Tuesday mornings. It required

moderate input by the Carers' Support Service Worker to sustain it. The Group also went on to develop a weekly social evening in a local pub which has been running for over two years. These evenings are aimed at local people and one of its members volunteers to drive and collect/drop off people who want to attend. Jim explained that the Group and this social evening, which is an extension of it, is much more than a gathering of people. Supportive activities take place beyond these meetings. For example, he said that most people share their phone numbers and are there for one another:

"Yes, well we've got everybody's phone number, and we've got everybody's birthday, you know... and we always fetch something in and have like a little buffet you know, and it just helps everybody, you know, it gives them a couple of hours away from their problems."

Furthermore, group members go out for lunch and shopping trips and such like. Often these trips were with another group called the Gemini Group which is an Over 50s group. As Jim illustrated:

"...and we do different things like that, when we get everyone on the bus to go out somewhere. We don't just turn them loose at the end there, we say 'we are going to so and so for lunch, are you on?' We'll go shopping, whatever, and then meet up for lunch, have a bit of a laugh and a giggle and then get on the bus to come home or whatever, or go back shopping, whatever time we've got you see, and everyone tries to pull together, everyone tries to enjoy themselves. If we have any spare seats on the coach or the bus, we let people come with us but they have to pay, we can't pay for them as well, but we let members bring guests as such to fill the coach up, so we can all help one another. There are lots of people who can't leave their house or whatever, then we get them in different ways that we can, you know, we try and talk to people on the phone; we try and find other things for them."

Jim explained that the Group did not exclude 'ex-carers' either, that is people who had lost the person they had previously cared for, for whatever reason. Joyce added:

"You don't have to be a carer to have problems. We look at it that way. An ex-carer... I think they need more help, you know, because they are down themselves, they've lost their partners or... and what have you."

In terms of wellbeing, Jim and Joyce had also personally benefitted from activities held regularly during the meetings whereby alternative therapists had delivered sessions including Reiki and Indian Head Massage and so on.

The couple made it very clear that they felt a carers' group of some kind was a 'life-line' for some people and had direct benefit for those who attended:

"...because I think when you are caring for people, you know, there are some in there and who they are caring for is really bad, and it just gives you that couple of hours away from them and you can have a laugh, have a game of bingo, because they are doing bingo at the moment and that, and it just helps them. You know, they forget about their troubles, just for that couple of hours."

It was also evident that Jim and Joyce were advocates of people in communities pulling together to support each other. Jim said:

"To me, helping others is the best thing to take your mind off it and it's the best way of getting on. You know, if you can support them, get something for them or do something with them, that's the best bet for me. I don't like to just sit around..."

The couple acknowledged that the Group was not attended by carers from ethnic minority backgrounds or younger carers, but made it clear that anyone from any background was welcome. The Group was about to advertise on the Internet through the social

networking site 'Facebook' and in a parish magazine. The advert had been designed already and stated that any carer or 'ex-carer' was encouraged to come along to the Group.

Both Jim and Joyce had benefitted immensely from their involvement in the Group both in terms of the support they received and gave. Their roles such as Treasurer (Jim) and as an active organiser (Joyce, in terms of selling tickets, arranging prizes, handling cash etc), kept them active in a way that clearly helped their local carer community. Both agreed that Joyce's involvement and responsibilities in relation to these activities had considerably brought her 'out of her shell' and had increased her confidence greatly. They very much valued the Group that had been developed as a result of the Carers' Support Service and both agreed that the Carers' Support Service Worker had "*done a marvellous job*".

Case study 2 – Peter's story

Peter's story provides an example of the outreach role of the former Carers' Support Service Worker in the Charlestown and Lower Kersal area. Peter was identified to the Carers' Support Service through other members of the community and the Carers' Support Service Worker paid him a visit at his home. At this time he was struggling to cope with a personal health issue and described feeling down and alone and did not know what to do. The Carers' Support Service Worker encouraged him to attend the Carers' Drop-in group at Charlestown. Peter's wife was in fact his carer and originally they attended the Group together.

At first he was not sure he would keep attending as he didn't think he fitted with the mix of people at the group – mostly older people – and he had a particularly jolly approach to life. However, his wife returned to work and he found the Group members very caring towards him which met a need he had at this time. Peter got fully involved in all the Group had to offer – trips, socialising, therapies e.g. massage, chatting with others - and felt that he blossomed as a result. After a while he felt able to actively support others and has developed into being a key figure within the Group and his local community. He explained that he plays a particularly important role in injecting humour into the Group but also more practical support such as being a volunteer driver to assist people to and from the meetings and other get-togethers. He has also

become an active participant in the local 'Time Bank' scheme whereby people exchange skills and services by the hour e.g. gardening for decorating. He had previously been a volunteer helping people to recover after stroke, but had found this too emotionally draining after a while and so gave it up. He has a number of other roles in the community such as a children's clown that have all come about through his involvement in the Group. Furthermore, he has supported the Carers' Support Service Worker in setting up a similar group in Weaste and Claremont.

When asked if he would have got involved in these activities anyway, regardless of attending the Group, he explained that this was definitely not the case:

"No. I would never have dreamed of it, well I would never have thought of it. But it's just... maybe it's just the different people that I've met and the... well the majority are very caring people that work there and they've always got time for you."

Peter explained that these positive experiences had brought him 'out of his shell' and that his wife was delighted by the change in him. She no longer has a carer role towards him and indeed it is him that now cares for others. He went on to clarify a point about the issue being one of *caring* and not necessarily about being a carer. Peter said:

"Yeah. You look after each other. No matter if you're caring for somebody, you're still caring for somebody else. If somebody feels a bit down, anyone not caring for them, I take them to one side and say, 'what's the matter?' Maybe you can't do anything but you can console them for a bit."

Whilst it is many years since he was first contacted by the Carers' Support Service Worker, Peter says he has seen her doing her more recent outreach work with others (in her SCDS Worker role), which he says is done in a very effective way. He illustrates this with this statement:

“...but she knows people’s needs right, she knows when she talks to somebody... she’s really understanding and each individual she explains to them what are your benefits, you know, you’ve got to be – what’s the word for it – I’ll come back to it in a minute, but you know, assessed, you’ve got to be assessed and all that and (the SCDS Worker) has got that sort of voice and that sort of, not authority, but she makes them feel at home. That’s what I’m saying like, you send a piece of paper out, people read it and, ‘what does this mean?’ you know, but if somebody like (the SCDS Worker), you talk to them, you feel...”

Peter had strong views about the sustainability of the Carers’ Drop-in groups that had arisen out of the current SCDS (and its predecessor). He said:

“I think that’s the part of being a carer, they need somebody to talk to and you... when you go to the doctors and they have leaflets? How many people pick a leaflet up? You know what I mean, they don’t. You go in... I haven’t looked at that yet, you know, but it’s all there, information and what’s going on. But rather than talk to her, explain to her about it, and that’s what (the SCDS Worker) is good at and she’s doing that at the moment. St Luke’s, she organised that and they’ve got a drop-in and... but that won’t last, it will fall apart because they don’t... it’s alright saying, ‘you’ve got to do this and you’ve got to make this and do that’, but then they’ve never done it before, you know, it’s like dropping in with a load of lions (lion gulping noise) gone! That’s my personal view of it, but I think she should stay at a placement much longer, because the work she doing is brilliant and to me if she has a year there then she goes to Irlam next, it’s a waste of time, a waste of time.”

Furthermore, Peter explained how the Carers’ Support Service had facilitated a sense of ‘community’ to develop through the Group

whereby people look out for the welfare of others through exchanging phone numbers, calling up should someone not attend when expected to, arranging birthday parties and so on. He went on to talk about the value of friendship:

"Friendship. There's not a lot of it knocking about and that's what's missing."

Peter had outlined numerous personal benefits from involvement in the Group. He enjoyed and felt better for receiving some of the therapy treatments such as massage that were provided at Group meetings. He had even started a counselling course which he confirmed was directly due to this involvement:

"I've always wanted to do counselling on alcohol, because I've been there, you know. I think I've got the Level one under me wings, you know what I mean. Rather than read a book, I've actually been there, you know. I can tell if they're kidding or not kidding, you know and yeah... I have, I've seen people crying and all that lot and it's heart breaking, some of the cases."

Interviewer - But would you be thinking of doing that counselling course if you hadn't gone through the carers? I'm trying to see what a difference the carers made to you.

No. This has opened my eyes. I'm going to sound like a kid, it's brought me happiness.

Interviewer - That's what I need to know.

The wife is happy because when I was drinking if I went out, my wife said, 'where you going?' Now, I'm out all the time and she's no worries or anything, or I'll ring her and say 'I'll be back late', 'okay then', you know and it's great. I've got my... I've got my own car now, I can do what I want."

Peter felt that support for carers was better since the Carers' Support Service and SCDS were introduced simply because there was no support previously. When asked about how future Carers' Development Services should operate, Peter felt strongly that there should be some kind of worker. He explained:

“Oh it's better than what they had because they had nothing before... and she (the SCDS Worker) was like the Messiah. They never had anything like... they had drop ins. But they had nowhere they could meet and have a talk about this and for carers themselves, you know. There again it goes back to leaflets. It's all been from information by leaflets. People were saying like, 'well I phoned this one and they passed me on to someone else'. That's what happens in offices, you phone something, oh that must be some... then they put you to another one, then you go to another one... you know, they keep on passing you round. But with (the SCDS Worker) I don't think you can do without her, I'm sorry, there should be more like her.”

In terms of information relevant for carers, Peter explained that a lot of it was obtained through word of mouth. The Carers' Drop-in group did not advertise and the Carers' Support Service Worker had been the main point of contact for information and for sign-posting to the Group, which was his preference. Peter was aware that he gave up a lot of his personal time for the betterment of his community. Whilst he was very happy to do this, there were a few issues that he felt could be addressed. One was greater attendance by the SCDS commissioners to come and meet the people the service was provided for first hand. Another concerned payment for petrol for some aspects of voluntary work e.g. a filming project he was doing that would save the funders a lot of money. Peter had struggled to get petrol reimbursement for this, which he felt devalued his contribution (resolved at the time of publishing this report). Overall, Peter spoke very highly of the Carers' Support Service and SCDS and indicated he would welcome a greater say in how the SCDS develops in the future.

Case study 3 – Barbara's story

Barbara's story is an example of how a carer was referred to the former Carers' Support Service by another agency. The Citizen's Advice Bureau had suggested Barbara access the service through its Carers' Drop-in group in Charlestown and Lower Kersal. She met up with the former Carers' Support Service Worker and discussed her caring situation and has been a member of the Group ever since (approximately 2 years). At that time she believed that there was nothing else for carers and so she found the service invaluable.

Upon joining the Group, Barbara had been caring for her son since he developed a serious illness 14 years previously. At first she describes being rather quiet and the Group 'brought her out of herself'. After a while, the Group had evolved and a change of committee members was needed. Barbara was persuaded to apply to the committee and whilst she just missed being voted in on this occasion, another Group was independently established in the locality by carers who left the original group. Out of this tense situation, an opportunity presented itself and Barbara is now Chairperson of this second Group. This appointment occurred at a time when the Carers' Support Service Worker had withdrawn from having direct involvement with the original Drop-in Group. The Group is now running very successfully again although it had benefitted from some external support arranged by the SCDS commissioners and management team, during this transition. The Carers' Drop-in group has just had to change premises from St Sebastian's Community Living Centre to new premises around the corner.

Barbara described how the Carers' Drop-in group focuses on being a drop-in facility for carers where they play games, arrange days out and so on. The emphasis is on providing somewhere to *"...de-stress and have a bit of 'me time' with other carers who are going through the same thing and it works because it brings you out of yourself."*

Group members have a laugh and prevent each other feeling depressed at their situations. Personally Barbara felt that involvement in the Group had made her a more expressive person and that sharing hugs is commonplace at the meetings, whereas previously she had shown warmth in a different way. Being

involved forces her to read and write more, even when texting, which she thinks is a good thing and has helped her improve. The social and support side of the Group was clearly very important:

“...yeah I love all the people there they're great really and they give me the same feeling back.”

Group members make a small payment when attending and every month the Group's Treasurer discusses where the Group accounts are up to. Barbara explained that originally the Group's funding came from the Council and Government but that groups now have to find their own funding which is quite a strain. Her own Group is going to have to apply for Lottery funding which she expects is going to be a hard process. Barbara made it clear that it was vital that the Group finds a way to continue. She said:

“...but like I say next year now we've got to do all our funding ourselves but we still get together, even though we had that period where there was upheaval with these other three people, we still kept coming and coming and coming because we need that, we need that two hours, if we could have all day we'd have all day!”

Advertising of the Group to other carers is a challenge. Barbara said they relied on other agencies such as the Citizen's Advice Bureau, word of mouth, the Carers' Support Service Worker, and whilst there is an advertisement in her GP surgery, other formal promotion is minimal. She felt that information through people's doors would be ideal. This suggestion included information for the people who are cared for as they too may not know there are places for them to go to (e.g. day care), which would take pressure of the carer who might find it difficult to bring up the subject. Whilst more information was needed, Barbara recognised that information such as in the Healthy Living Centres would only reach people who attended them.

In terms of ideas for anyone setting up a new Carers' Drop-in group, Barbara had the following advice:

“I should imagine it's a matter of finding a room... there's a free room over there at the

doctors, when they last checked there was a free room there, but the ladies at our centre, with them living down that area and they're elderly some of them... find it a bit hard to travel. So it's to find a room. It's to find somebody that's willing to support it and get it running and get it up that would be the first thing to do wouldn't it... the first thing is the room and then get your information out and leaflets and that. I'd put leaflets in every door but there we go."

Barbara hopes there will be many more similar Carers' Drop-in groups in the future as she believes that is what is needed and what carers want. She also highlighted the plight of young people and felt that they needed something similar especially for them.

Barbara feels that the Carers' Support Service Worker played an invaluable role for carers like her. She explained:

"Anyway it has been fantastic she (the Carers' Support Service Worker) does some good work... You know anything she can do for you she'll do. If you want any appointments or counselling she'll do it for you. She never lets you down. It's been fantastic and you know she's set other places up now. Yeah she's a good person; she really goes out of her way for you."

Case study 4 – Sandra's story

Sandra's story is an example of how the outreach role of the SCDS sought carers through an existing community group. Sandra's husband has a chronic health condition and she cares for him at their home. Sandra met the SCDS Worker at a meeting of Salford's Older Peoples' Forum. Along with two other people, she has since gone on to take over the Carers' Drop-in group that was initiated twelve months previously by the SCDS in the Claremont and Weaste area, and is presently the Group's Chairperson. The Group currently meets on Wednesday afternoons for three hours. Activities centre on refreshments, information exchange, visiting speakers such as health workers and games, that essentially give carers time out from caring. Ex-carers are welcome too.

Sandra thought that it was important that the Carers' Drop-in group was encouraging of ex-carers to attend. She explained:

"Yes, yes. Because we feel that, even if you have been a carer, there are a lot of issues that have not been dealt with, especially when there's hardly any help for carers; I'm certainly sure there's a lot less for ex-carers. And they can help us and talk about their experiences and share things that they've gone through or benefits they've put in for or... aids and things like this, to help us. It's like a two-way thing really..."

Sandra went on to explain the benefit to ex-carers of being linked in with the Group:

"It just gives them a bit of... it's a weird thing, really, that, isn't it? Just a bit of satisfaction, I think, that, although they're not caring, they're still useful."

Despite being open to everyone, Group membership tended to be older adults and those who are from a non-ethnic minority background. Sandra explained how the Group was actively trying to publicise itself and had recently produced a poster to display in public places as well as local media coverage. Sandra felt quite strongly that what was lacking was a community notice board in a location such as the library in Claremont. Presently information exchange was through word of mouth of Group members, email (for the limited number of people who had computers) and the Salford Advertiser newspaper. Sandra hoped that a Lottery fund application that the Group had recently submitted would help with providing equipment such as a computer and printer. Currently there were personal costs to her voluntary role on the Group such as printing on her husband's printer which was costly. Similarly, her husband, who has a disability, drives people about in his car on behalf of the group and does not claim for this. Sandra highlighted how much voluntary work is done on goodwill and how in reality, she has always ended up out of pocket in her voluntary roles over the years.

Sandra felt that being a 'carer' had become a topical issue in recent years whereas in the past carers were a hidden group. One of the good things about being 'discovered' is the visits the Group gets from health workers and such like:

"Like, we've got the nurse coming to do the Carers' check; I've never heard of that before. We've got ... the PCT come regularly; that's nice. We've got other people... there's a group of carers, who'll come and use you or get information from you because we're so rare. We're not hanging about on street corners; we're either at the doctors, at the hospital with the one you're looking after, or you're stuck in the house."

She made a plea for better understanding of how things are for carers:

"We're hard to get hold of but I'd like our worth to be appreciated more. When you've got someone in hospital, they're the main person; they get all the attention. Yes, it's good but what about the people who've got to care for them? To me, they've come out of hospital; I'm not medically trained but I had to learn to be. I've had to learn to say to my husband: 'Do you need to take your insulin?' or 'Do you need something sugary?' I've had to learn to read his body language because he's ended up diabetic but no-one's come along and said to me: 'You'd better go for some training for that'."

Sandra and the two other committee members had taken over running of the group at the time the SCDS Worker had completed her twelve month allocation to the Claremont and Weaste area. Sandra was sure the Group would have folded if they had not stepped in to run it and that there would then have been nothing for carers of this sort. She highlighted the challenge presented to volunteers such as her in running such a group. She explained:

"It takes a certain sort of person to run one of these groups because, yes, you're working all

week to keep it going and, yes, we would like to go in and go 'oh yeah, somebody's looking after me' but we found out there wasn't anybody so it's got to be us. It could be a lot better and I hope when we get the money (Lottery funding) and we feel a bit more secure in where we are... Because, one of the ladies is 75; she's never done any fundraising or filling in a form so it's all new to her. And we've got a girl that's run round telling everybody their rights and helping them get housing benefit for years, so that's good. And they've got me that's a carer but I also have filled in forms for money and got committees going, and things like that, so it's good but it could be better. We're hoping to improve."

Sandra had very strong views about the current SCDS model whereby the SCDS Worker only works in an area for a twelve month period.

"And we all felt sad that she'd (the SCDS Worker) gone and it was quite stressful. It was, like, yes, you've come to help us but have you helped us because if I waken this sleeping... I won't say a monster but a sleeping situation that are we better just to struggle on or people saying: 'Yes, you need help', but where is it after 12 months? And we've had to go and find that help; we've had to put in for a Lottery bid; we've had to find somewhere to go that's suitable - three ordinary people; not anybody that's qualified."

Interviewer - is that not a good idea that you get to take over the reins yourself, as it were?

Maybe. Maybe another 12 months rather than it being shoved on us because our saying is: what if we hadn't have been there to take over? And I said this when I first met (the SCDS Worker): 'You people come to Salford to get all your statistics and everybody agrees and then, when the funding goes, you go, and we're left. We're

not qualified to do anything but we'll struggle on'. I said: 'And that is what's happened in Salford'. Because, I used to be very involved in the Church so I've seen this myself. They get people in: 'Oh, we need this, you need that, oh, yes, you do'. And then when the funding has gone, they go, as if money is everything. Well, money isn't everything; some of us can't just walk off. So, I think, another 12 months, and I think she'd agree with that, as well, because there must have been people she's not been able to reach. There must be people we've not ... other than if she knocked on every door in Salford, I don't really know how else you're going to reach them but we would have liked at least another 12 months."

Sandra felt that she was much less depressed after being supported by the SCDS Worker and then working to keep the Group going also gave her encouragement that something was being done for carers. In particular she had welcomed having a 'Carers' check' at the group recently. One benefit of there being a group was that she felt it kept her mind off her own situation and she was thoughtful about being able to care for others whilst caring for someone herself. Whilst there is a Carers' Centre in Salford, Sandra felt it was not ideally located for people like her who would need to be able to walk to it and all she felt she got from it was a newsletter. Her Carers' Drop-in group did refer members to the Carers' Centre should they need specialist information concerning such things as benefits and other agencies. The need her group successfully addresses is to provide somewhere for carers to meet and support each other, which would not otherwise be available. Sandra felt that the SCDS was invaluable and needed to remain in an area for no less than two to three years. Her overriding concern was that volunteer work such as hers with the Group was a money-saving exercise for the authorities and that there was little appreciation of the emotional side of it.

Case study 5 – Neil's story

Neil's story is an example of the outreach role of the SCDS Worker in the Claremont and Weaste area. The SCDS Worker approached him in the local shopping precinct and they discussed how Neil

cares for his daughter who has a learning disability. Neil was already known to the SCDS Worker due to her working and living in the area for many years. Neil was encouraged to attend the Carers' Drop-in group which he has been doing regularly since.

Neil has put forward ideas into the Group which went on to be run by a committee, but that is the limit of his involvement. Neil described how the Group gets visited by health workers and other agencies and how the committee manage such things as Group finances through various roles e.g. Treasurer. Its main purpose is as a 'get together' to give carers a couple of hours respite to chat and play card games and such like. Neil said there were also a small number of events such as a Christmas do. Several Group members are happy to use their own vehicles to enable people to attend the Group and associated activities. Members pay £2 each week to pay for refreshments and a Lottery fund bid for funding is in progress.

Neil confirmed that the Group met his expectations as a support network and explained how members would ring each other up should they fail to turn up at a meeting when they had been expected. He found this 'being looked out for' very reassuring and pleasant. It was something he had not experienced prior to the Group being set up. Whilst he was aware of the Salford Carers' Centre and received its newsletter, he enjoyed the service that only the Carers' Drop-in group provided and so in that way he felt things were better for carers since the SCDS came into his area and the Group was formed. The ease of access to the Group, with it being very local to him was an important factor. He also enjoyed the therapies the Group provided such as massage. The opportunity to have some fun and a bit of banter at the meetings clearly lifted his spirits every week whilst his daughter attends a day care centre. Practically as well as socially the Group has helped Neil navigate a major benefits problem he had to deal with and members rang up the Citizen's Advice Bureau for him and engaged their support. He was sure that without the Group he would not have known where to go with this problem and it would likely not have been resolved.

In terms of future drop-in carer groups, Neil did not think having them in every area would necessarily work. The issue was not so much about there not being *enough* carers to attend but about

whether they *would* attend such a group which isn't everybody's preference.

Case study 6 – Jamie's story

Jamie's story is an example of how a carer got to know about the SCDS through word of mouth. For the last twenty five years, Jamie has been the carer for his now elderly brother who has learning difficulties. This caring role involves a lot of physical care as well as day to day practical support. Since Jamie's wife passed on four years ago, he has become the main carer for his brother. He does have some caring support from other family members on occasion and is able to get away on holiday once a year without the brother he cares for.

Like other carers from the Claremont and Weaste area, Jamie has been making good use of the Carers' Drop-in group that used to meet at St Luke's but now meets each Wednesday afternoon at the Chandos Grove club. The set up of this Group was facilitated by the SCDS Worker back in summer 2009. Jamie was told about the Group by some fellow carers and so he went along to see what it was all about. Jamie describes the focus of the group as being one whereby members support each other with any problems they may have although he himself does not feel that he currently has any particular problems. He describes how Group members help to keep each other's spirits up when sometimes caring for someone can wear you down a little. Telephone numbers have been exchanged and generally members have a get together and a laugh at meetings. Jamie describes additional benefits as being massage lessons currently run within the Group and socialising opportunities with other people.

Furthermore, Jamie described being involved in some local filming to make a DVD about being a carer. He explains that involvement in the Group has led to these opportunities and he actually feels his life has been enhanced as a result of it. Jamie does not have a formal role within the group but does help anyone who needs help wherever he can. He describes informally encouraging people to join the Group in addition to publicity leaflets the Group puts in public places. Information exchange between Group members also occurs.

Jamie's suggestions for development of future Carers' Drop-in groups included better funding to enable members to get out and about on trips and perhaps with the person they care for. He felt that the SCDS had made things much better for carers as "...*there wasn't nothing; there was nothing for carers, nowhere for us to go...*". He would also like the Carers' Drop-in group to be available more times during the week, perhaps two or three times, as he believes that the support carers get there enables them to be able to care better. Jamie's view was that there should be an outside 'authority' to help fund the Group and facilitate events and so on, rather than it just being down to group members.

Case study 7 – Carol's story

Carol's story provides an example of the outreach role of the SCDS Worker. Somebody who knew Carol and her caring situation mentioned her to the SCDS Worker who made an approach. Carol cares for her elderly husband who has a chronic health condition, yet she manages to work four days each week.

Carol was very happy to be approached by the SCDS Worker. She had given permission for her contact details to be passed on and the SCDS Worker quickly worked out when Carol was off work and got in touch. Carol describes the SCDS Worker as 'lovely' and found her very approachable and supportive. She found it very helpful to have someone listen to her talk about her caring situation and found she off-loaded a lot of stress by having a good discussion with the SCDS Worker. As a result, the SCDS Worker identified Carol was eligible for a Flexible Carers' Grant and this was successfully applied for.

Carol was made aware of the Carers' Drop-in group in Claremont and Weaste but chose not to make use of it. This is because she preferred something that she and her husband could do together on her set weekday off work each week and so she joined a local singing group which met this need. She would otherwise be interested in attending, and especially taking part in the therapy sessions such as massage, but she feels she gets a lot of support from her own circles of friends including those that have grown out of the singing group. She also uses some of her Flexible Grant to support alternative therapy sessions and so she gets her 'me time' that way. Carol had largely had her caring circumstances assessed prior to SCDS involvement and so other than listening

and emotional support, and the Carers' grant, did not feel she made further use of the SCDS. On the day she shared her story, she was being assessed for further support in terms of greater input by a paid carer and District Nursing Services for her husband. Carol felt that the support she had received from the SCDS was invaluable as she had not realised just how stressed she was. Carol described the SCDS Worker's style of approach:

"...I'm a great rambler and she just sat and let me ramble and said 'oh well we could do this, and we could do that but we need to know what people will go to', and it was such a softly, softly approach that you found yourself saying things that you didn't realise you were thinking. A bit of a confession really. It was very gentle, very warm and very friendly so it's a shame that she's gone really."

Carol felt that the SCDS would be invaluable for new carers. She explained:

"One of the things I did say to (the SCDS Worker) was that her service would be excellent for newly diagnosed people, simply because it's like a bolt out of the blue. Everything goes to pot and you can't think, you don't know what to do and you don't know who to approach and suddenly you've fallen down and there's no way of getting up on your own and that was what happened to me. That is one of the things we did talk at length about is the fact that it's like a one-stop shop. You get a diagnosis and basically... the medical people all know that you've got XYZ to go down but there's nobody there to do it for you. There's nobody there to talk to you."

Carol went on to illustrate how skilled support for carers such as that provided by the SCDS Worker can be so beneficial, as the trauma of becoming a carer can be great. She said:

"I mean his (her husband's) diagnosis literally floored me because I was off work for five

months. I couldn't go to work; I couldn't even get up the next day. I couldn't make a decision to get up. Everything just went and that was when you need the help you need somebody to point you in the right direction. You don't always listen, don't get me wrong but for there to be somebody there and I think that, to me, is the benefit of this (Carers' Drop-in) group. Somebody that's four years down the line that's been there had to pick themselves up, ask for the help, get this, this and this and is on, you know, a bit of an even keel, then it's continuing group work or the therapies of whatever, but I think that new thing is the most important because people ... you have no idea it's just absolutely devastating."

Whilst Carol did not access a Carers' Drop-in group herself, because her needs were met elsewhere, she did feel that any future SCDS should comprise of local groups. She explained:

"Well I think they should be... perhaps a lot more locally set up groups, just to keep it... you see because people won't travel far so you're better off with smaller groups being set up. If you think of Salford as it is, you could say have one in Weaste and then if the next one's in Broughton - I'm not going to go to Broughton and they're not going to come to me - so it's got to be kept local. I think that is the important issue and have the same people there. What I wouldn't want is to be going in and saying 'what about the person I've come to speak to?' So it's I think keeping staff, getting the right kind of staff is also very important and keeping them there. I mean like for (SCDS Worker) at the Broughton one, she'd made that group her own but you can't take that expertise with you if you're only setting up a group because people know that you're only there for a certain length of time and that main body has gone. You've got to leave somebody that's worked closely, that knows what the aims and objectives are and knows how it's runs and

knows how it works for people because all groups of people are different. People will want different things at different times with their caring role and it's quite a lengthy service this because I mean some people will be carers for years and some people it's quite short. And I think it's local knowledge, local research of what the local people want because as I say I mean when she (the SCDS Worker) came to me 'oh yeah it's a brilliant idea' and yet I've not accessed the service so that to me says well it wasn't that brilliant, but yes it is. It's my circumstances that have stopped me going – or my choices. Whereas somebody who's housebound or at home all day with somebody it will be a godsend.”

When asked if Carers' Drop-in groups as a model should be organised solely by carers themselves, Carol had a strong view. She explained:

“I think that these things fall apart. You've got to have one kingpin that keeps it all together, that keeps it all moving. I agree yeah you don't have to have somebody there day to day, but I think people like the same faces. People that they know, people that they trust that's hard to build up if your staff keeps changing. If you go in there and you've got a different face everyday... people need trust. You learn not to trust people. I had that pointed out to me only on Tuesday – you need to learn to trust people but I can't because he's (her husband) my responsibility. If I wanted to go somewhere for help and advice and that person wasn't there I'd think twice about going again. So yeah, it's all 'power to the people' but I really do think you need a regular kingpin, somebody there, 'oh well it's okay we won't come, we'll go and see them on Tuesday when I know they're there and I think you'd find a lot of people do that '... a lot of people would do that because a lot of people again, depending on their circumstances don't want the

responsibility of running anything, they want to turn up again, selfish, when they want something because that's human nature, people go when they want something. I've done the same, you know you ring up - when I need something."

Overall, Carol considered the SCDS an invaluable service that she would have used more if her caring situation had developed more recently and she hadn't already got involvement of a number of health and social care services.

Case study 8 – Andy's story

Andy's story is an example of the outreach role of the SCDS Worker in the Little Hulton area. At the time of being contacted by the SCDS, Andy was caring for his mum who had multiple health problems. In the past he had been in employment and lived away from Salford. Five years ago his mum had a fall and a social worker appointed at the time suggested he move in with her to look after her. He never moved out. In the early years he did not know to claim for benefits he was entitled to for his caring role and received no respite. Challenges are presented when he has to go and care for his brother's dogs when he goes away on work trips. At these times he has to prepare his young niece to care for his mum and manage her day-to-day needs such as meals etc. His situation made Andy feel very stressed.

Andy was approached by the SCDS Worker in his community shop and his caring situation was discussed. As a result the SCDS Worker arranged a social worker to assess his circumstances. He now has a social worker he is very happy with and has all of the benefits he is entitled to and equipment is in place such as ramps and hand rails. At the time of him sharing his story, he was awaiting a day care assessment to be undertaken for his mum. He expressed feeling much less stressed now and really looking forward to some respite. Andy felt the SCDS was "great" and had done him a lot of good.

Case study 9 – Lee & Katie's story

Lee and Katie's story is an example of the outreach role of the SCDS Worker. Lee cares for his partner who has a chronic health

condition which means she needs help with dressing and walking. Her condition is generally worse during the winter months. They have three cats and a dog that they care for.

With permission, a welfare benefits worker highlighted the couple's situation to the SCDS Worker who made an approach at a local Resident's Group. After discussing their situation, Lee was encouraged to attend a 'Men's Group' on a Thursday and Friday. He expressed liking this group very much as he enjoyed playing games and meeting others. Without the involvement of the SCDS Worker, Lee said he would not have known that any help was available to him. He had previously got a bathing chair for his partner but now has a Carers' Allowance. He is keen to develop new skills especially about building things. His partner is developing her reading skills at college and he feels more confident about the future. He felt that setting up of a Carers' Drop-in group in his area (Little Hulton and Walkden) would be a good thing to give him a bit of time to himself and to give his partner some 'space'. Lee felt such a group would be a good place to talk with others in his situation and for mutual support, but did not really view it as a means of reducing stress. Katie later joined in with the conversation and agreed with Lee's views and added that he often had to 'think' for her. For example, when she has medical appointments, she felt she could not take in all the information being given to her and so Lee had to listen for her and explain later. Lee and Katie both felt the SCDS had been "great" and that Lee was very much benefitting from the support of the Men's Group he now regularly attends in particular.

Case study 10 – Pauline's story

Pauline used to care for her mum for many years and then her husband went into hospital a few years ago for treatment of a chronic chest condition. The hospital staff at that time had arranged for benefits and home adaptations to be assessed for and provided. Pauline has arthritis herself and on bad days both her and her husband care for each other. Pauline pointed out that they did not see themselves as 'carers' as such. This was a label that is commonly used but they are simply a married couple. She saw caring for her mother previously as a daughter's duty.

When sharing her story it was clear that Pauline already had Carers' Allowance and all of the equipment she needed at home to

support her husband. Pauline felt that she had not benefited anything directly through the SCDS although she had appreciated having the SCDS Worker making sure she had her needs fully met. Pauline said she had heard talk in her area (Little Hulton and Walkden) of a possible Carers' Drop-in group. Pauline felt that self-help would be a good thing rather than trying to gain support through an 'official worker'. She believed that many carers were greatly affected by stress and would benefit from such a group. Pauline also recommended that information about support for carers should be promoted in the local 'Housing' newsletter.

PART 5

Discussion

The style of this report has conveyed the 'voices' of participants as individual personal stories. Yet there are a number of common issues and shared concerns that resonated amongst participants, as well as isolated views, that we will discuss next in an attempt to put across an accurate and truthful picture of what people told us about the SCDS. Views included:

- That being a carer can be very demanding (but enjoyable)

Participants were willing and open in explaining the circumstances surrounding them becoming a carer or taking on a carer role. Several participants saw a difference between *being* a carer and *caring* for someone. Whilst some were happy with the label 'carer', others saw this label as ill-fitting as they considered themselves to be doing a duty or doing what any other spouse/partner/family member would do in similar circumstances – that is supporting their loved one. Whilst all participants found the caring role they undertook to be demanding, both at the time of becoming a carer and in undertaking the role of a carer since then, all expressed that they were happy to do this. No-one we spoke to was new to caring so all had come to terms with their situation although for several participants, the transition to becoming a carer had been sudden and quite a traumatic experience. Being a carer was often enjoyable but every day was a challenge and for some was a continuous 'hard slog', for which they welcomed any support available.

- That carers have very different circumstances but shared several common issues

A number of particularly common themes presented in our discussion with participants. There was a widespread need for emotional support, such as de-stressing opportunities and space to talk about problems relating to caring and more general life issues. Similarly social activity (having a chat and a laugh, getting out and about), information exchange (about what is available e.g. grants, what is going on e.g. events, support with grant applications etc) and practical support were the other main needs participants had.

- That Carers' Drop-in groups were appreciated

Emotional support and a social outlet were needs that most participants felt were met through membership of a Carers' Drop-in group. It is acknowledged that most participants interviewed attended Drop-in groups and so the views of those who do not attend such groups is under-represented. Such groups were considered an excellent solution to needs that would otherwise largely go unmet by existing mechanisms (such as Salford Carers' Centre), according to participants. The importance participants placed upon having somewhere to meet other carers cannot be stressed enough. The social activity embedded within these groups and opportunity to share and gather information, were the other two main needs which were well met by the Carers' Drop-in groups. Therefore participants who attended these found them invaluable and a key means of coping with their caring roles. Simply having somewhere to go with like-minded people in a similar situation was a very important issue to almost all participants. Where participants were not a member of a Carers' Drop-in group, they explained they got such needs met elsewhere – at other social outlets e.g. a men's group or existing personal social networks. The core activities that the drop-in group model comprised included: talking time, refreshments, games, social events, trips out (sometimes with other community groups and/or the 'cared for' person), complementary therapies and so on, and these were strongly viewed as being the right approach. Also for groups to be committee-led and income generate for themselves to some degree (such as members paying a modest charge to attend, seeking external funding) was considered to be a good model.

- That there was added value from the SCDS in that it impacted on health and wellbeing

Participants felt that the relief and support gained from the SCDS Worker directly and Carers' Drop-in group attendance, significantly affected their ability to cope which in turn had a positive impact on their health and wellbeing. Health impacts mostly pertained to feeling less stressed and as a consequence depression was viewed as less likely to be experienced. Complementary therapy treatments delivered at the Carers' Drop-in meetings were highly valued and felt to decrease stress and/or promote relaxation.

Other impacts concerned an increase in confidence (when in public, in one's own abilities, in going about daily life etc), self belief/esteem, friendships, peer support/caring, a wish to locate opportunities for paid work and/or contribute in a meaningful way to participant's local communities, voluntary work, self-development e.g. new skills such as applying for funding and managing groups, and improved financial situation once grants had been awarded.

- That carers should lead Carers' Drop-in groups

There was recognition of the value of carers themselves leading Carers' Drop-in type groups but there were a number of challenges they need help with that could otherwise limit their success. These include having enough of the right people available to form a core to take up the challenge of setting up a group or to take over an existing group. Aptitude and skills in applying for funding e.g. to the Lottery fund were considered important. Whilst appropriate skills could be learnt it was felt that there had to be sufficient people willing and able to do this and that it was not easy. Having sufficient time and ability to run groups in terms of the personal demands this placed and skills required were seen as key potential barriers to success. Commonly carers do not have a lot of time beyond their caring roles and bidding for funding is a particular skill.

Participants said that managing what they described as 'personality clashes' amongst group members was particularly difficult and presented a major risk to groups' success. Members had not been prepared for such issues and welcomed the input of an external facilitator or the SCDS Worker to help them work through such issues when they presented.

Finding suitable premises in suitable locations was also key to success and participants had experienced significant challenge in finding suitable premises in terms of accessible location and facilities (not too far from the population they served, comfortable, warm), that were also affordable.

Promoting and advertising the groups and reaching other carers was also a skill that participants felt they lacked and needed support with, although they had clear ideas about how this should be done e.g. local Press, community information boards in

libraries, leaflet drops through people's doors (to reach those who do not get out and about much), Facebook, Parish magazine, and Internet.

- That the SCDS outreach function is highly valued

A key element of the SCDS is its outreach function. Most participants had originally been identified to the SCDS Worker in this way and being approached directly by the SCDS Worker or referred to her by a friend or other agency was considered highly acceptable. Much of the success of this aspect of the SCDS was attributed to the personality of the SCDS Worker and manner in which she made her approach, put people at ease and empathised with their situation. Participants valued the fact that the SCDS Worker has caring experience herself which they felt helped her understand their circumstances. In the majority of cases, the SCDS Worker spent a good amount of time giving emotional support to participants on first meeting them which they found invaluable. Participants were then linked in with Carers' Drop-in groups (either in setting them up or creating them where they did not exist) so that they had an alternative source of support. That said, the ongoing presence and availability of the SCDS Worker locally, and her continued input into Carers' Drop-in groups (albeit reduced) once they became self-operating, was considered important.

Several participants highlighted other impacts of the SCDS outreach function in addition to emotional support. Access to financial assessments enabled several participants to apply for grants they had not known existed or did not know they were eligible for (e.g. Flexible Grant). Others received the input of various health and social care workers that proved beneficial to them or the person they cared for such as respite care (day care services) or increased hours of carer provision in the home. Some participants were signposted to other groups for support e.g. a men's group.

- That having an SCDS Worker is very much wanted

Participants were very clear that they felt a carers' development service with a dedicated carers' worker was their preferred model of support to help them with caring successfully for their loved ones. The personality and style of service delivery of such a

person was viewed as key to its success. Participants liked the face-to-face aspect of the SCDS. Such a person/role was considered the lynch pin of carers being able to cope. A small number of participants did not feel they personally benefitted from the SCDS Worker in practical ways (in terms of referrals, financial assessments or new information etc) but that was because they felt 'linked in' with other support mechanisms prior to the SCDS Worker undertaking her role in their area. These connections had been made as a result of events such as a hospital discharge process for the person they care for. All participants had felt emotionally supported by the SCDS Worker who they valued for taking time to listen to their issues upon meeting them and beyond.

- That things are better for carers as a result of the SCDS

Participants all expressed life being better for carers in their locality as a result of the SCDS. They felt the Service met their own needs in relation to support to be a carer, which were previously largely unmet in their view. Whilst some had previously gained information or assessments for grants etc through health and social care workers and Salford Carers' Centre, most had not and many claimed that they did not know of the existence of Salford Carers' Centre prior to coming into contact with the SCDS Worker. Whilst the SCDS Worker raised awareness of other services that were available to carers, what these services were felt to lack was a person who would spend time with carers and with whom they could build a rapport. This ongoing relationship with an individual was highly valued and should not be underestimated.

- That any carers' development service or worker should remain in an area longer than 12 months

Due to the popularity of the SCDS it is perhaps unsurprising that participants ideally wanted such a service to be a permanent feature in local carers' support. However, many recognised the need to use financial resources wisely and that other areas of Salford should be permitted to benefit from the SCDS Worker rather than a minority. They maintained however that the SCDS Worker should remain in an area for an absolute minimum of 12 months but ideally should be present for 2-3 years. Participants generally accepted that Carers' Drop-in groups were only one aspect of the SCDS to-date and that these could be successfully led by carers themselves. They did however stress the challenge

that this presented them and they felt that SCDS service commissioners may not fully appreciate the fragility of such groups nor the demands placed on “*ordinary people like us*”. They believed that without skilled external facilitation and support to both prepare them and equip them to function successfully, including help with facing challenges along the way such as disputes amongst members, that groups’ sustainability would be significantly threatened. Only one participant expressed that carer’s communities should take responsibility for their own groups after an initial period of facilitation. Participants generally felt that the SCDS work was incomplete after a twelve month period as only some carers will have been reached. They strongly believed that there was a large population of ‘hidden’ carers as they described them, who needed to be rooted out by the SCDS and who would be overlooked in its absence.

- That needs of different groups of carers require meeting in other ways e.g. young carers

Many participants acknowledged that membership of Carers’ Drop-in groups may not represent the wider population of carers in Salford. They expressed concern that there was a ‘hidden’ population of more isolated and perhaps older carers, who did not readily leave their homes who went unidentified by the SCDS and other agencies who could put them in touch with sources of support. Those participants who were members of Carers’ Drop-in groups said that they were welcoming of carers from any background including younger people and people from non-white British backgrounds, but nobody of these backgrounds had joined a Carers’ Drop-in group. A small number of participants were aware that Salford Carers’ Centre has a service for young people who are carers and expected their needs would be met by that. Whilst participants were aware that the vast majority of carers in their areas were not members of Carers’ Drop-in groups, they still felt such groups were important as they met the needs of some carers who did prefer that kind of forum.

Participant also stressed the importance they placed on being available for people who are no longer carers as the circumstances through which their caring role ended were likely to be upsetting. They therefore felt that at such a time, those former carers needed even more support. They also recognised that ‘ex-

carers' had valuable knowledge and experience to share and draw upon to support existing carers.

- That Carers' Drop-in group members would like attendance of SCDS commissioners/managers at their meetings

Several participants that we spoke with who were members of a Carers' Drop-in group expressed a wish for a greater presence of the SCDS commissioners/project managers at their group meetings. This was so they could raise any concerns relating to the SCDS directly and gain a direct response. These participants thought that these personnel did not fully understand their needs and perceived them not to care. It is important to note that at the time of the interviews, these participants had recently (between 6 and 18 months) undergone a difficult transition process of having the SCDS Worker move from their locality, to work with carers in a different area of Salford.

PART 6

Implications for practice

In summary, participants highlighted the following:

- That being a carer can be very demanding (but enjoyable)
- That carers have very different circumstances but shared several common issues
- That the SCDS is highly valued
- That having an SCDS Worker is very much wanted
- That things are better for carers as a result of the SCDS
- That any SCDS service/Worker should remain in an area longer than 12 months – ideally 2-3 years if not continuously
- That carers' drop-in groups were preferred and committee run groups with refreshments, self funding activities, games, social events, therapies etc is a popular approach
- That there was added value from the SCDS in that it impacted on health, wellbeing and personal development
- That there was recognition of the value of carers themselves leading drop-in type groups but there were a number of challenges they need help with and that can otherwise limit their success. These are: having the right people available, applying for funding, time, ability to run groups (skills, personally challenging), personality issues, suitable premises in suitable locations, promoting and advertising the groups/reaching people
- That needs of different groups of carers require meeting in other ways e.g. young carers
- That there is a wish for a greater presence/involvement of SCDS commissioners/managers in meetings with carers

What this evaluation did not aim to uncover, and may be the goal of any future evaluation, is the views of people who are 'cared for'. This project report was only ever intended to illuminate the voices of a small cross-section of carers who had used the SCDS to give an insight into the perceived value of the Service and is not representative of the wider population of carers in Salford. The findings resonated well when verified with members of a Carer's Drop-in group.

Issues to consider for practice therefore include:

- 1) A need to heed these carers' preference for drop-in groups with sufficient external support and facilitation over an adequate timeframe
- 2) A need to recognise the added value participants identified as a result of the SCDS in that they felt healthier, better able to cope, more confident, more outgoing, more engaged in their wider communities and gained useful new and transferable skills
- 3) A need to recognise the high value attributed to the SCDS and the importance participants placed on face-to-face contact by the SCDS Worker
- 4) A need to recognise the high value placed on the outreach aspect of the SCDS and its effectiveness in reaching otherwise 'hidden' carers
- 5) A need to provide sufficient initial resource (personnel and finance) for groups to become skilled and supported to become self-operating and self-sustaining over time and without premature withdrawal of these
- 6) A need not to underestimate the importance and complexity of personality and group dynamics in fostering relationships between the SCDS Worker and carers and also between carers themselves
- 7) A need to build in evaluation of any revised delivery of carers' support from the outset to capture the learning about what works, with who, and in what circumstances

APPENDIX

Salford Carers' Development Service – Carers' Interview Guide

1. How did you come to know about the service/group?
Prompt: Word of mouth, contact by (the SCDS Worker)?
2. How have you been involved in the service/group?
Prompt: Formal role eg treasurer or informal role eg tea maker at meetings
3. How is the service/group run?
Prompt: Where, who, times, frequency, social activities, peer support? How does (the SCDS Worker) operate? Does it meet the needs of the community eg young carers?
4. What is the purpose of the service/group?
5. How well does the service/group do what you expected it to do?
Prompt: Purpose as you view it, your expectations as to what it could do for you
6. What are the positives/challenges/learning points/issues you wish to raise?
7. Is the support for carers in your area better since the Carers' Development Service started?
8. How can the service/group be improved?
9. How has involvement in the service/group affected you as a person?
Prompt: Such as confidence, health, free from harassment, dignity/respect
10. How has involvement in the service/group affected your ability to care for someone/others?
Prompt: Such as breaks, choice & control over your/their day to day life, financial impact
11. How did you get information through the service? How helpful was it?
Prompt: Via (the SCDS Worker), the group, signposted to another organisation, via other carers
12. If another area was setting up a carers' development service, what would you recommend they consider?
Prompt: With hindsight and the learning from areas receiving the service to-date, how do you think any future service should be delivered differently?

13. What would you like to happen with the findings from this evaluation project?

Prompt: Who should receive the findings, how would you like them to respond?

14. Is there anything else you would like to say?

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